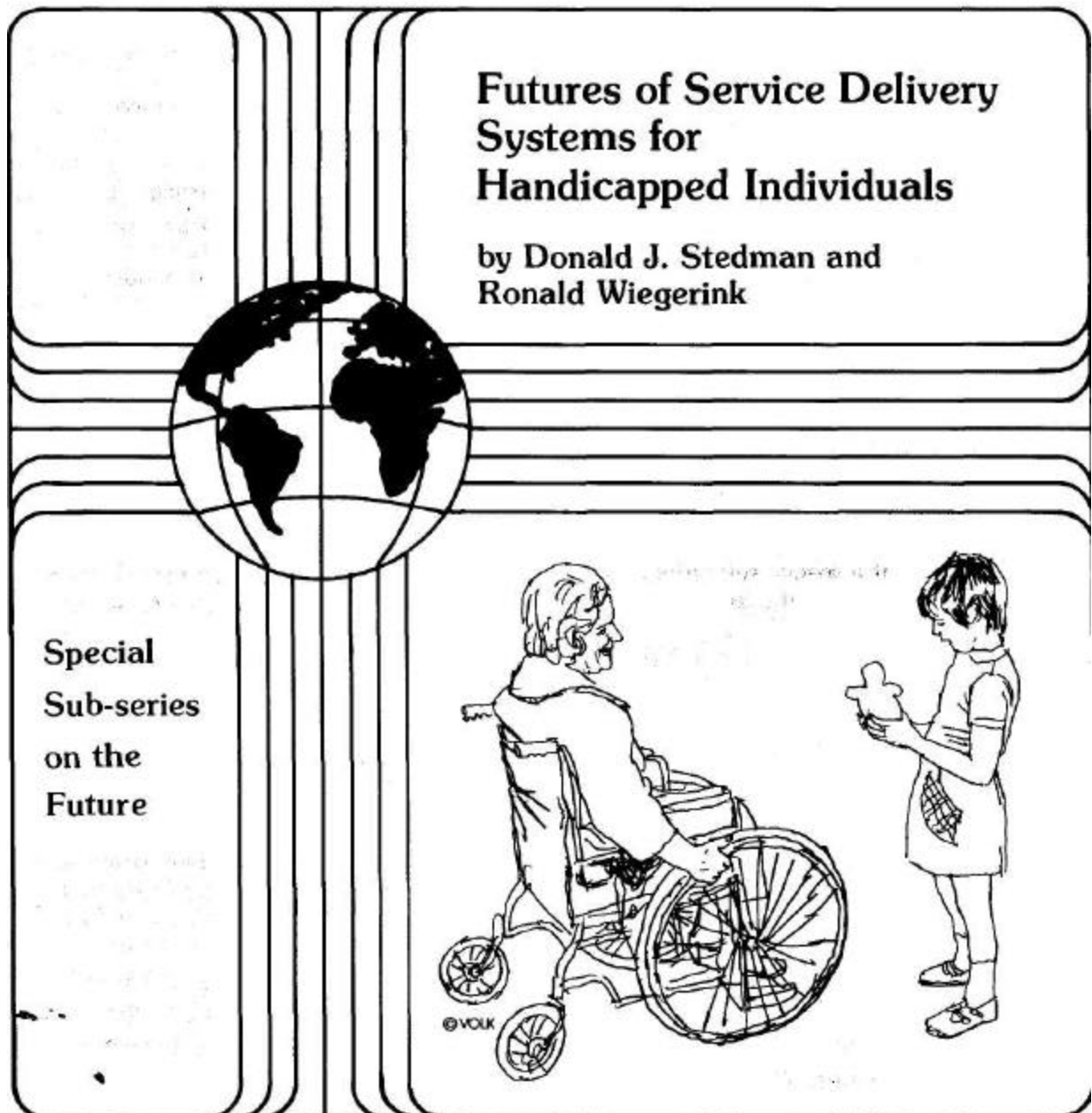


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themes 8 issues

A Series of Topical Papers on Developmental Disabilities



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DD Themes and Issues is a series of topical papers for this nation's Developmental Disabilities Planning Councils. Each participating state, territorial, and District of Columbia Council develops and implements a comprehensive State Plan for the coordination of comprehensive services for citizens who are developmentally disabled.

This paper is part of a special sub-series on the future and is intended to broaden the vision of the DD Community about the issues and problems which everyone must face in the remainder of the twentieth century.

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Futures of Service Delivery Systems for Handicapped Individuals

by Donald J. Stedman and
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Introduction

For nearly 200 years this country has been attempting to devise an effective program of services for handicapped individuals in the communities of America. However, it has only been since 1950 that significant strides in the direction of comprehensive services have been taken. It has only been during the last decade that notable achievements have been reached.

Part of the progress has been made, because national attention has been drawn to the nearly 25 million persons in our society who have special needs due to some handicapping condition. Much of the gain has been a result of expanded research in the area of human development and rehabilitation. A large amount of the success is due to comprehensive approaches to health, social and educational problems and issues from the national level. Major generic programs such as social security, the poverty program, economic development, comprehensive health and insurance, and programs designed to improve the quality of life all help identify and reduce the incidence and impact of handicaps on the person and society.

Special federal and state legislation, and consequent service program development, from the time of the Kennedy Administration to the present day—notably the Comprehensive Mental Health-Mental Retardation laws, the Veterans Administration laws, the Economic Opportunity Act, the Rehabilitation Act, the Civil Rights Act, the Maternal and Child Health laws, the facilities construction laws, and the Developmental Disabilities Act—have created a fabric of activity which sets the stage for effective action.

The climate for providing services to meet the needs of the developmentally disabled is now more promising than ever before. Most of the needed legislation, legal decision, and monies are now available and ready to be used and accessed. The primary services needed by the developmentally disabled are known; they need to be put in place. There is the rub. Present funding and service configurations are not designed to readily facilitate the development of comprehensive services at the local level where they are provided. Instead, Federal and state mandates and categorical funding often serve the opposite purpose; they thwart comprehensive coordinated services. But just as laws and resources have been made available to provide for the disabled, so too should the necessary service configurations. In order to provide these service configurations, some current issues must be addressed.

7. *The Integration of Human Service Systems*

There has been an ever expanding rhetoric on this topic over the last few years. General statements of problems and goals constitute the bulk of the statements coming from all levels, both public and private. Essentially, the discussions and presentations on the "integration of services" and the need for an improved method of integration and coordination amount to a body of general belief or prevailing philosophy that is commonly held by professionals and the special interest groups which comprise the constituencies of this effort, especially in the area of handicapped individuals. In a report by Gage (Integration of Human Services Delivery Systems) it is stated that the Department of Health, Education and Welfare regards the impact of HEW services as less than the sum of its program parts. This is said to be due to:

- a) service programs are not correlated with a common set of *national* goals and service objectives.
- b) they are not responsive to the *multiple* needs of the clients that they serve.
- c) they are not *orchestrated* through centralized, comprehensive planning processes of state and local levels.
- d) they tend to be *narrowly* prescribed and *rigidly* regulated.
- e) they not only fail to complement one another, they typically *do not mesh* with other federal programs inside or outside of HEW.

In addition, the problem of integrating service programs includes a variety of subfactors. The political value of remaining unique helps maintain a competitiveness between agencies and specialized service programs that works against the integration of human service programs at all levels. The difficulty of developing a common or shared information data base slows down the movement toward attempts to develop better integrated service systems.

The development and implementation of services along strictly disciplinary lines tends to hold up cross-agency or inter-agency programming. There is a continued resistance to cross-disciplinary or trans-disciplinary training and manpower development also. Interdisciplinary service and training programs are badly needed.

At the current time there is a slow but steady trend toward integrated human services agencies at the local (county) level which help blend health, mental health, rehabilitation, social services and other programs rather than maintain the current, separate generic agencies. At the top (the federal level), there is an attempt to blend together health, education and welfare or social services programs within the Department of Health, Education and Welfare. This situation might well be inverted to the point where a separate, cabinet level, federal agency would be established for health, for education, and for social services that would provide coordinated planning and the development of criteria, policy, regulations and monitoring activi-

ties for an increasingly integrated system of state and local agencies. In other words, the current situation where the local agencies are separate and poorly coordinated and the national agencies are attempting to come into a more blended configuration, should be inverted to separate federal agencies into special cabinet level programs while the local programs are becoming more blended or integrated. This inversion would allow for a shift away from direct service delivery by federal and state agencies toward a program development, resource development, technical assistance, monitoring and evaluation role and could place the local (county and municipal) agencies into a more direct, effective, integrated service delivery pattern.

2. Meshing of Planning, Service, Research and Training

The flow of information and activity through the sequence of planning, program development, program implementation, research and development, evaluation, and training is poorly carried out at the present time at all levels. There is a need to orchestrate the planning, resource development, and program development activities of service and training programs, including higher education as well as field-based training and education programs. Further, it is necessary to articulate planning and program development activities with the research, development and dissemination programs which are increasingly remote from the service systems and the training programs designed to staff the service systems.

A regional policy, planning, service, training and program development mechanism should be put in place that would provide for the unique service program responses that arise from the special local, state and regional service needs of handicapped individuals. This regional meshing activity would bring together the necessary information, planning, service, training and research and development programs, and would result in a more effective articulation and delivery of services than is now available.

3. Improved Match of Consumer-Client Input with Agency-Organizational Input in the Development and Delivery of Service Programs

While consumerism has increased at a dramatic rate since the middle 1960s, the Developmental Disabilities Act is the only major piece of federal legislation currently being implemented at the state and local level that requires consumer involvement and input into the planning, program development and service delivery activity for handicapped individuals. The involvement of consumers, especially the handicapped, is an absolute necessity to improve the quality, timeliness and propriety of the service needed as well as to guarantee that an appropriate and objective evaluation can be derived in the face of mounting service program costs.

A Center for the development and study of consumer involvement in human services programs should be established to complement the federal, state and regional organizations now in place.

4. *Install a Monitoring, Evaluation and Feedback Activity into the Planning Process*

At the moment, information developed for planning, service, training or research programs in the area of the handicapped is not sufficiently accurate or fresh to assure the timely and effective delivery of service. Monitoring the effectiveness of programs, evaluating programs and providing feedback to the planning and program development activity from the monitoring and evaluation activities is poorly accomplished. In addition, there is an urgent need for the development of cost-benefit studies, particularly research, into the appropriate measures of input and output of human services programs that would allow for more effective evaluation. Cost-benefit studies, thus far, have not yielded useful units of measurement or methodological approaches that would result in the program evaluation and cost-benefit statements that are available to industry and agriculture.

A special effort should be mounted to focus the issue of measurement, methodology, and systems for monitoring, evaluating, improving planning and developing cost-benefit strategies for programs in the area of handicapped individuals.

5. *Review The Merits of Public Education Programs*

Millions of dollars have been poured into propaganda, public awareness and public education programs in the mental health, special education, rehabilitation, health, and other human services and human development areas. There have been differential effects, mostly measured by success in fund raising. The provision of *know/edge* to the general public about handicapped persons does not necessarily result in improved *understanding* of the nature of handicapping conditions. Neither does it always result in a positive change in the attitudes of the general public toward the handicapped and the positive contributions that the handicapped are making in our society. Further, the mobilization of public interest and public support for service, training, and research and development activities in the area of the handicapped has not been as effectively accomplished as is necessary to mount the public support, attention and resources necessary in the years ahead to *prevent* handicapping conditions and to provide for the special service needs of those who are and will be handicapped in our communities.

A special effort must be undertaken to study the variety of strategies which have been used effectively to mobilize public support for other issues. In addition, new approaches to public education and the strengthening of our effort to increase public awareness in the area of the handicapped must be undertaken, particularly among lower socio-economic groups. Without a background of moral and financial support for the variety of programs needed to serve handicapped individuals, no further progress can be made and recent gains will be lost.

6. *Closer Coordination of Governmental Branches*

The route taken by special interest groups (notably parents) toward developing service programs for handicapped children and adults has changed. The emphasis was shifted from pressures on legislators and congressmen for specific legislation, to pressures on the executive

branch of state and federal government for more enlightened leadership and to a legal advocacy which maximizes utilization of the judicial branch on behalf of handicapped individuals (notably class action litigation).

There needs to be a more effective, non-partisan coordination among the legislative, executive and judicial branches with regard to leadership, legislative development, and legal support in order to develop a more integrated and effective network of human services programs for handicapped individuals. A mechanism should be established to assist states toward a better orchestration of legislative activity with executive agency implementation which "fits" with the judicial and legal interpretation and enforcement activities within states. In short, what we may *not* need is further litigation. What we *do* need are successful demonstrations of how current consent decrees can be fulfilled.

7. The Provision of Adequate Financial Stability Directly to Handicapped Individuals

Social security, insurance benefits (both public and private), stipends, tax relief, job training, job provision and other individual support strategies must be expanded and increased for handicapped persons so that an inadequate income does not hamper the handicapped person from otherwise coming to grips with the problems of community, family and personal adjustment. A national program supported by state and local agencies and the general public must be initiated which will provide a guaranteed income through a variety of individual financial supports to handicapped persons so as to assure the personal welfare of each handicapped person in our society.

8. The Application of Technology to the Problems of Handicapped Persons

A recent, belated effort on the part of the federal government to transfer some of the technological products developed during the active years of the space program (NASA) constitutes one of the few efforts to systematically review the current and developing technologies (hardware and soft ware) which could be applied to alleviation of those conditions which handicap many of our citizens or to prevent the existence of those conditions which lead to handicap. The utilization of visual communications technology for diagnostic activities in rural areas, new types of materials for prosthetic devices, computer-based instructional systems for the mentally retarded are but a few of the many opportunities that may lie in a systematic review of the full spectrum of technological development experienced in this country over the last 30 years which might be of some immediate and long term value for handicapped persons. Similarly, those special inventions developed for handicapped persons (deaf, blind, retarded) might be of great benefit to other special populations in our country and around the world.

9. End the Continued Focus on Defect Rather than on Environmental Determinants and Arrange the Environment to Prevent or to Alleviate the Effect of Handicapping Conditions

The continued notion that a *handicap* is a *defect* results in persons being labeled and seen as *deviant* in the general society. This works against the best interests of the handicapped

person and retards or perhaps precludes advances in the adequate understanding of handicapping conditions and the development of adequate service delivery systems to meet the needs of handicapped individuals.

Greater support should be given to developing and expanding the base of knowledge which has grown over the last few years which takes an ecological approach to the understanding and alleviation of the effect of handicapping conditions, especially mental retardation. Environmental and socio-cultural determinants of handicaps are poorly understood. Improved research, development and demonstration service programs need to be mounted in order to more fully explore this major source of handicapping conditions and handicapped persons and the extent to which environmental manipulation and cultural redefinition might provide satisfactory remedial and preventive measures.

10. The Role of Higher Education

Higher education, particularly graduate schools and community colleges, are still inadequately involved in the training effort required to develop and implement a comprehensive and effective service delivery system for handicapped individuals throughout the country at the local level. The traditional role of higher education as the source of knowledge generation must change significantly in the direction of a needs-related training strategy which includes joint planning with service programs. In this way, the data base necessary to plan and develop service programs can be shared between the manpower development organizations and the service delivery systems with a consequent orchestration and synchronization between the two systems. The current situation where service programs are being planned and developed only to be stalled by the lack of adequate numbers and types of personnel is unnecessary and unforgivable given the state of the art of our current planning and evaluation skills.

Higher education is, in most instances, available and willing to participate in the development of objectives, priorities and strategies for meeting the service needs of handicapped individuals. However, an extra effort must be made to help link the institutions of higher education with the service delivery systems, especially at the state level, in order to assure adequate joint planning and program development and the successful development of competent staff, on time, for the necessary service programs. This will require special block funding to universities for correlated work with service agencies.

/1. Continuing Back-up Support Systems for Services

Insufficient attention has been paid to the need for continuing technical assistance organizations, to provide for in-service training, staff development, consultation, resource development and the program assistance necessary to service programs on a continuing, back-up support basis. Demonstration programs, information dissemination, skill development, capacity building and technical assistance are a necessary part of any comprehensive service delivery system. Dissemination is an expensive process but one which is necessary if research products are to reach practitioners.

Technical assistance is a process whereby new knowledge, materials, special skills and information about related service activities can be brought to even the smallest element of a comprehensive service network in a systematic way. Technical assistance organizations, typically limited to small state and regional agency staffs, must be expanded to provide the kind of continuing support and assistance necessary to help mount a significant local service delivery effort.

12. *Inadequate Relationship Between Public Education Agencies and Human Resources Agencies*

Over the past several years nearly two dozen states have created "umbrella agencies" which have brought together mental health, health, rehabilitation, social services and other human services agencies under a common bureaucratic format. In no instance is public education included in these umbrella agencies. The net effect can be to make one of the largest enterprises of value to the handicapped individual more remote from health and other human resources programs. It is important in each state to develop and maintain an adequate planning, coordination and evaluation linkage between education and other human service programs at the state level. The situation may be particularly acute in states where state education agency heads are *elected* and the other state agency officials are *appointed*. Often this situation results in differing political backgrounds and constituencies which can work *against* effective inter-agency program planning and program development.

This type of partisan and unnecessarily differentiated agency activity should be circumvented where possible. Cross-cutting programs such as an Office for Children, a Department of Administration, a legislative analysis unit, or others can be initiated in order to soften the effect of the remoteness often found between education and other state agencies around the country.

13. *Education Represents the Greatest Investment of Resources*

Despite the fact that education represents the greatest investment of resources and perhaps is of the greatest developmental benefit for the handicapped, documentation and research from the field have been relatively sparse when compared with other areas of service affecting the handicapped, such as vocational rehabilitation. However, because recent litigation and legislation are highlighting the educational needs of the handicapped, it is likely that the quantity and quality of documentation in this field will dramatically increase. This, along with a national commitment to provide full educational opportunities for all handicapped children by 1980, demands more information than currently exists. Consequently, the need for educational research, development and dissemination (now at an all-time low ebb) is greater than ever. Personnel and funds for field-based research on practical educational problems should be developed at the federal and state level. A minimum of 15% of the service delivery system budget for education should be earmarked for research, development and evaluation.

14. Lack of Services to Eligible Persons

There are currently numerous federal and state programs, designed to serve the handicapped, that are not fully enrolled. In some cases, only about 50% of those eligible for the programs are being served. Such programs as Supplementary Security Income (SSI), Early Periodic Screening, Diagnosis and Treatment (EPSDT), and Vocational Rehabilitation programs for the severely handicapped are significantly under-utilized. This is primarily due to a lack of public awareness and aggressive outreach by these programs. It is also due to the fact that the programs are not currently prepared for full enrollments in terms of finances, manpower, and organization.

Service providers must be reorganized and prepared to enroll and serve eligibles. Services need to be promoted through public awareness campaigns. To cut costs, the red tape of screening must be reduced. When new services are developed, they should be tied as closely as possible to generic services and combined with the outreach, screening, and registration of other services directed toward the same populations.

The high cost of services, limited enrollments, service gaps, and lack of outreach is due to the fact that many services addressed to the handicapped are administered out of separate agencies. For example, services such as screening, food supplements, day care, early education, parent counseling, and health care for handicapped infants and toddlers are often provided by social services, public health, education, mental health and even some private agencies. While each of these agencies may have an important role to play in the delivery of services, the duplication of administrative costs and the gaps and duplications of services must be reduced.

Counties and other local districts must develop single "ports of entry" where *all* service entry points converge and administrative costs are shared. This would help assure cooperation and coordination of service providers, increased public awareness, and reduce the need to search for services.

Single agencies should become responsible for the administrative costs, supervision, and coordination of services for different age levels. For example: public health from pregnancy to age five; public schools from age five to sixteen; vocational education and rehabilitation from age sixteen to twenty-one; social services from age twenty-one and up.

15. Expensive Service Delivery Models

Many of the models of service delivery for the handicapped were developed with limited intentions and under unique service situations. Because of this, many of the service models now in use have become extremely expensive, for example, institutional care and self-contained educational classrooms. Less expensive models to deliver better quality services must be utilized, such as handicapped children in regular classrooms with resource support.

The long run cost-benefit of service models must be determined and projected so that models employed will be cost beneficial in the future, financially and socially. For example, developing 50 to 100 bed facilities to replace large institutions may be cost effective now, but over the long run may produce the same high costs of our current outmoded institutions. Solutions closer to the mainstream of life are less likely to continue to require special costs over the long run.

16 Lack of Adequately Trained Personnel

Services for the handicapped, more than ever before, require personnel who are, at the same time, both generalists and specialists. Service delivery personnel need to know their specialty. They also need *transdisciplinary training* (how to use other disciplines) in order to respond to the handicapped on a variety of dimensions and to know *when* to access other specialists. Current personnel do not often provide the full range of services needed. Too often, they access expensive, specialized services when not needed. Personnel planning services face the same dilemma; their specialized knowledge actually limits their usefulness. Manpower trained in a variety of human services areas (public health, education and social service planning) are needed to adequately plan the coordination of comprehensive services rather than to continue the current uncoordinated, categorical and specialized services.

In-service training in transdisciplinary decision-making for key service personnel and human service systems planners is desperately needed. Pre-service and in-service training, and technical assistance systems are needed to provide such continuing education for key service personnel.

17. High Overhead Costs of Federal and State Programs

Federal and state program costs have shown a demonstrative and significant increase in the last few decades. This is largely due to the confusion and mixing of planning, decision-making, administering, monitoring, evaluation, reporting, and service delivery costs.

The federal and state agencies should *contract* for services delivered, thus retaining only the planning and monitoring costs and cutting the overhead costs of direct service delivery. Federal and state government should provide block grants to private and public agencies closer to the service level. These grants should be provided with carefully defined standards of service but with limited specifications of methods of service to be used. Federal and state governments should get out of the business of providing direct services.

New Directions

It should be evident from this paper that the major need today is orchestration, consolidation, integration and the improvement of the quality and effectiveness of the activities we now have. Therefore, a major emphasis on bold new thrusts and directions is not here recommended.

Here are six innovative, new direction suggestions that should be considered:

1. There is a need for expanding and *decentralizing our policy development and program evaluation processes*. These functions have long been centralized and isolated from the main body of the service enterprise. Regional and local policy development activities need to be mounted in order to improve the quality and quantity of direct services to handicapped individuals.
2. We still work largely without a *comprehensive data base of information* necessary for effective planning, resource development, client tracking systems and monitoring procedures. Without the rapid development of a comprehensive and shared information and data base, no national network of services can be effectively developed or evaluated.
3. The clear need for *continuing support of service program activities* begs for the establishment of regional and local technical assistance, evaluation, staff training and management programs. Unless the service machine is continuously oiled and adjusted, it will soon be come obsolete and sputter to a non-productive halt. Technical assistance organizations, both public and private, should be continued and expanded with the major focus directed toward the development and maintenance of effective service programs.
4. The integration of services and the coordination of planning and program activities has been cited before. However, *new models of coordination, collaboration, and integration of services* should be developed from a basic and applied research effort. Funds should be made available to engage organizational research and development activities to improve our attempts to maintain effective, coordinated and integrated service systems.
5. We have yet to fully mount a comprehensive *preventive services program* which would include health, economic, educational and social services. The fundamental and long range answer to the problem of handicapping conditions is to prevent their occurrence. Comprehensive research, development, training and demonstration services need to be developed in the area of prevention.
6. Finally, a continuing and escalated effort must be maintained in the area of *advocacy on behalf of handicapped individuals* and the modification of public attitudes toward the handicapped and their place in our society. The deviancy model is still too widely held. Evaluation is still conducted toward exclusion rather than inclusion. The focus on employability and a productive slot in the corporate state still overshadows the equally, or perhaps, more important goal of improving human development and the quality of life for the handicapped person.

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